# The right to refuse treatment: ethical considerations for the competent patient

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A patient's right to determine his or her treatment is fundamental and reflects our respect for the autonomy of the individual.[1,2] The historical origins of this principle can be traced to philosophic treatises of the French and English Enlightenment.[3] In order to respect autonomy informed consent is obtained before any course of treatment; this allows patients to make treatment decisions based on the most information possible. Although usually viewed as a legal concept informed consent is essentially an ethical imperative to promote personal well-being and self-determination.[4] The principle of autonomy has been expressed in law by Justice Cardozo.[5]

Another principle deeply ingrained in our culture is that of the sanctity of life.[6] Resolving conflict between the principles of autonomy and the sanctity of life can be difficult. What does one do when a competent adult patient decides on a course of action that may shorten his or her life, as in the case of a Jehovah's witness who refuses a potentially life-saving blood transfusion? The Jehovah's witness does not want to die but is prepared to do so because of a religious conviction. In North America we would respect this competent patient's autonomy and right to refuse medical intervention.[2]

The case of Elizabeth Bouvia[7] further clarifies our current ethical and legal framework and extends the concept of medical treatment to include nourishment. Elizabeth Bouvia was a 28-year-old quadriplegic woman who was suffering from severe cerebral palsy and degenerative arthritis. Except for the ability to move a few fingers of one hand and some slight head and facial movements she was immobile. She was in continual pain. The feeding tube had been inserted against her will, and she wanted it removed.

The court in this case decided that a competent patient has the right to refuse any medical treatment, including nourishment and hydration. Furthermore, the court felt that the patient's decision to stop treatment and let nature take its course was not equivalent to her taking active measures to commit suicide (e.g., through an overdose of medication). It was recognized, however, that "all decisions permitting cessation of medical treatment or life support procedures to some degree hasten the arrival of death. In part, at least, this was permitted because the quality of life during the time remaining in those cases had been terribly diminished."[7]

This case differs from that of a Jehovah's witness in a number of ways. The Jehovah's witness who refuses a blood transfusion does not wish to die but wants, in fact, the best available alternative care to stay alive. Elizabeth Bouvia's request to have the feeding tube removed was not based on a religious belief but on the wish to shorten her life because of her suffering. She was competent and firm in her resolve. Her situation differs from that of a suicidal patient who takes an overdose, because her condition was the outcome of a disease and not of any active measures that she took. We can empathize with her suffering and her consideration of quality of life. The competent person is in the best position to determine which treatments are appropriate.

For informed consent to be valid the patient must be competent. The assessment of a patient's decision-making capacity is usually implicit in the doctor–patient interaction[8] and does not require formal testing. The law presumes patient compe-

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tence.[8,9] However, a patient's refusal of treatment when the benefit:risk ratio is very favourable may necessitate a more stringent standard of patient competence.[10]

In addressing competence two types of error need to be prevented. First, competent patients should not have treatments imposed on them. Second, incompetent patients should not be allowed to suffer the harmful effects of their bad decisions.[4,11,12] Attaining the right balance can be difficult.

There is no universally accepted definition of competence. The ability to communicate choices, understand information about a treatment decision and appreciate the situation and its consequences are among the legal standards commonly used.[8] Less frequently employed is the rational manipulation of information — the use of logical processes to assess the risks and benefits of various treatment options; the ability to do so may be impaired by a psychotic thought disorder, extreme phobia, panic, anxiety, depression, euphoria or anger.[8]

In the United States the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research[4] concluded that decision-making requires possession of a set of values and goals, the ability to communicate and to understand information related to the task at hand (although these abilities are not solely cognitive since they ordinarily include emotive elements) and the ability to reason and deliberate about one's choices. The commission rejected as the standard of decision-making capacity any test that looked solely to the content of the patient's decision.

The Ontario Electro-convulsive Therapy Review Committee[13] tried to define the concept of competence by including a consideration of the patient's ability to incorporate the information provided when responding to a physician's recommendation. This element was intended to correct some of the difficulties associated with more narrow definitions of competence and was elaborated as follows: patients should be judged incompetent if (a) they are unable to express a settled choice or their desires constantly fluctuate, (b) their treatment choice is founded entirely on delusional beliefs or (c) they have a mental disorder resulting in an emotional state that prevents them from applying the information learned about the treatment.

The risk, however, in evaluating a patient's emotional state to determine competence is that this might result in an infringement of a competent patient's autonomy. One approach would be to reserve the most stringent and demanding standard of competence for people who are faced with decisions that are life-threatening and contrary to public and professional rationality. Drane[12] stated: "When diagnostic uncertainty is minimal, the available treatment is effective and death is likely to result from treatment refusal, a presumption is established against the refusal of consent to treatment." This type of evaluation would involve both cognitive and affective elements.[12]

One can critize the assessment of emotional state to determine whether a patient is able to use the information provided in reaching a treatment decision. For instance, a finding of emotional incompetence may be only a convenient way of overriding a patient's wishes; what is considered irrational is sometimes a value judgement.[14] One of the forces that has helped nurture the growth of the principle of autonomy over the last three decades has been society's increasing moral pluralism and the attempt to prevent personal values from being encroached upon.[3] Nevertheless, too rigid an adherence to a narrow definition of competence that neglects emotional factors may compromise a patient in life-threatening circumstances.

The following is a case that was debated by a panel of the Royal College of Physicians and Surgeons of Canada.[15]

A 52-year-old woman had a heart attack and within 4 days showed signs of acute mitral regurgitation. After initially refusing she agreed to undergo cardiac catheterization. The findings led the treating physician to tell her that she would die within days without mitral valve replacement. She refused the operation, and a psychiatrist was called in. He concluded that she had a personality disorder, and although frightened of dying she was probably more frightened of the surgery. He felt that she could be declared incompetent, although both he and the treating physician thought she understood the consequences of her action. The patient survived surgery and agreed to a second operation when the replacement valve failed a few months later.

The panel concluded that the physician had acted inappropriately by operating on the patient. Among the arguments made by panel members was that one cannot overrule a competent patient's decision on the chance that the person might be grateful later. Another panel member added that because the law presumes competence the burden of proof would be on the physician. The reason for the panel's judgement was the conviction that the decision of a competent patient had been overruled.

A broader definition of competence[13] that takes into account emotional state when assessing the patient's ability to use information would probably have been more appropriate in this case. The evidence that the patient's competence may have been compromised was that she agreed to a second operation after the replacement valve failed. This

suggests that her initial refusal was prompted by extreme anxiety, which diminished as a result of experience with the procedure.

Jonsen, Siegler and Winslade[2] stated that physicians have a legal duty to respect a patient's wishes concerning treatment even though that patient may be anxious or depressed. However, they did feel that physicians should do whatever is in their power to counter the effects of anxiety or depression, for example through education and vigorous persuasion.

This last point is particularly important given a disturbing attitude that I have discerned among some interns and residents. In a case similar to the one described a resident thought that it was not his responsibility to determine why the patient refused the life-saving operation but only to explain the options and their consequences. This distancing from patients reflects a misunderstanding of the principle of autonomy and is contrary to an ethic of healing.[3]

It is essential that physicians strike an appropriate balance between helping patients overcome the irrational fears that prevent them from pursuing promising treatment options and respecting the different weights people give to the avoidance of pain and suffering.[16] The exploration of these fears and reservations, combined with education by the health care team at appropriate intervals, is ethically desirable and should result in more favourable outcomes in such cases.

Pellegrino and Thomasma[3] felt that "overly hasty decisions not to treat (out of deference to the principle of autonomy) may be more damaging to the patient's best interests than some degree of paternalism." They said that patient autonomy should be one of the goals of treatment but not to the exclusion of all other considerations and that a model of treatment that maximizes the good (beneficence) to the patient is the most appropriate.

Jonsen, Siegler and Winslade[2] presented the following case.

A young man who had signs and symptoms suggestive of bacterial meningitis was informed of the diagnosis and told he needed treatment with antibiotics. He refused the treatment without giving any reason. The physician explained the extreme dangers of going untreated and the minimal risks of treatment, but the patient persisted in his refusal. Apart from the strange refusal he exhibited no evidence of mental derangement or altered mental status.

The view of Jonsen, Siegler and Winslade was that the physician had a moral obligation to pursue this matter further, particularly since the risks of treatment were low and the benefits great. The authors reluctantly concluded that given the enigmatic refusal and the urgent and serious need for treatment the meningitis should have been treated even against the patient's wishes if this were possible. They recommended that legal authorization should have been sought if time permitted. Pellegrino and Thomasma[3] felt that the principle of patient autonomy would be wrongly exercised if it resulted in the rejection of penicillin treatment for meningococcal meningitis, since the disease is life-threatening and is likely to result in residual damage to the central nervous system even if the patient recovers.

It was later determined that the patient had refused the treatment because a cousin of his had died several years earlier of anaphylactic shock as a result of having been given penicillin. This case further illustrates the need to explore a patient's resistance to treatment, particularly when the decision does not appear to be promoting his or her well-being.

The following example highlights the confusion about competence and patient autonomy.

A woman was driving on a highway when her car slammed into a pole. She was relatively lucid when taken to hospital. The neurosurgical team explained that her spinal cord had been transected and that she was a quadriplegic, but with proper physiotherapy and good care she might develop some arm movement. With the help of a prosthesis she could eventually be expected to feed herself and perhaps even learn to use a typewriter. However, because of the swelling around her cord and her difficulty breathing mechanical ventilation might have to be used temporarily. The patient stated that she did not want it. The neurosurgeon, believing that the accident had left her incapable of sound judgement, was prepared to use mechanical ventilation even though a psychiatrist felt she was competent.[17]

If competence is defined solely as the ability to understand and appreciate the information conveyed the patient could be considered to have been competent in the emergency situation. However, if all the factors had been appraised — including whether the patient's emotional state allowed her to use the information provided — she would not necessarily have been deemed competent. The patient was making an impulsive, irreversible decision immediately after the emotional trauma of being involved in a serious accident and having learned of her quadriplegia. An informed decision should allow for adequate reflection.

Pellegrino and Thomasma[3] stated that in an emergency "physicians should always act to reverse trauma or illness in spite of contrary expressions until the condition is judged irreversible and hope-

less, or until the patient's current wishes are demonstrated as antedating this new event and perduring to the present."

The right to self-determination in health care is fundamentally sound. However, a strict adherence to the principle of autonomy can be problematic when patients appear to be cognitively competent but unable to make use of the information because of their emotional state. It is essential not to abandon these patients but to work closely with them in determining why they are making decisions that do not appear to be promoting their well-being. This exploration, combined with ongoing education by all the members of the health care team, is ethically desirable. Further research will need to be done on the concept of competence to determine how it could be broadened to include emotional factors. In the interim, a useful course of action would be the one outlined by Pellegrino and Thomasma[3] of attempting to maximize the good to the patient.

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## *Conferences*

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**Aug. 9-11, 1991:** Federation of Medical Women of Canada Board of Directors Meeting and Educational Session (in conjunction with the 124th Annual Meeting of the CMA)
Sheraton Centre of Toronto
Federation of Medical Women of Canada, 106-1815 Alta Vista Dr., Ottawa, ON K1G 3Y6; (613) 731-1026

**Aug. 11-16, 1991:** Ontario Medical Association section meetings (in conjunction with the 124th Annual Meeting of the CMA)
Hilton International Toronto
Ontario Medical Association, 600-250 Bloor St. E, Toronto, ON M4W 3P8; (416) 963-9383, fax (416) 963-8819

**Aug. 14, 1991:** Canadian Medical Protective Association Annual Meeting (in conjunction with the 124th Annual Meeting of the CMA)
King Edward Hotel, Toronto
Canadian Medical Protective Association, Carling Square, 560 Rochester St., Ottawa, ON K1G 5K7; (613) 236-2100

**Aug. 18-23, 1991:** 5th Congress of the International Psychogeriatric Association
Rome (previously planned for Jerusalem)
Dr. M.O. Agbayewa, Riverview Hospital, Port Coquitlam, BC V3C 4J2, (604) 524-7038, fax (604) 524-7250; or Dr. M.R. Eastwood, Clarke Institute of Psychiatry, 250 College St., Toronto, ON M5T 1R8

**Aug. 23-25, 1991:** 2nd World Congress of Acupuncture and Natural Medicine (with precongress course Aug. 21 and 22 and postcongress course Aug. 26 and 27)
Conference Hall, Beijing International Convention Centre, Beijing
Steven K.H. Aung, chairman, 1210 First Edmonton Place, 10665 Jasper Ave., Edmonton, AB T5J 3S9; (403) 426-2760 or 426-2764

**Aug. 26-29, 1991:** 7th International Conference on Pharmacoepidemiology (sponsored by the International Society for Pharmacoepidemiology)
European World Trade and Convention Center, Basel, Switzerland
Dr. Stanley A. Edlavitch, conference chair, International Society for Pharmacoepidemiology, University of Minnesota College of Pharmacy, HSUF 7-158, 308 Harvard St. SE, Minneapolis, MN 55455; (612) 624-4426 or 624-5931, fax (612) 624-2974

**Sept. 1-6, 1991:** 6th World Congress in Ultrasound (sponsored by the World Federation for Ultrasound in Medicine and Biology)
Copenhagen
Congress Secretariat, Spadille Congress Service, Sommervej 3, DK-3100 Hornbaek, Denmark

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